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ABSTRACT

Four documents, intended for specific audiences, touch on screening and social integration of handicapped children. The first, for policy makers, reviews classification categories and describes early detection devices and prevention measures. Policy implications of integration within families, communities, and schools are considered. The second document, intended for nurses, midwives, social workers, teachers, and parents, defines disability conditions and provides a simple checklist for screening. Social integration and mainstreaming provisions are discussed. The third document, for academic level workers and professionals, covers the role of screening in medical practice, primary prevention, and screening in early childhood. Support needed by families in order to take advantage of social integration is discussed. The final document covers the subjects of screening and social integration for mass media specialists. (CL)

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International Children's Centre

1980

SCREENING AND SOCIAL INTEGRATION OF HANDICAPPED CHILDREN

A DOCUMENT FOR POLICY-MAKERS

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MAGNITUDE OF THE PROBLEM

It has been estimated that about 140 million of the world's 1400 million children under the age of 15 are disabled. Their distribution in different parts of the world is uneven due to the great differences in the socioeconomic state of development, poverty being one of the most important factors favouring various forms of disabilities. In 1975 there were about 18 million disabled children in Africa, 88 million in Asia, 11 million in Europe, 13 million in Latin America and 6 million in North America. These figures will increase by about 35% by the year 2000 unless some radical change can be introduced to provide effective preventive measures and rehabilitation services.

CLASSIFICATION

The causes as well as diagnostic categories of various impairments and disabilities are manifold. Among the most prevalent causes, the distribution of which is often different in the developed countries as compared to the developing ones, are infectious diseases, malnutrition, congenital defects and accidents. The ensuing handicaps can be divided into several groups such as children with :

- locomotor problems, due for instance to birth injury, poliomyelitis, accidents.
- visual handicaps ranging from the blind to partially sighted, especially fre-

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quent in countries where trachoma or vitamin A deficiency prevail.

- hearing handicaps ranging from the deaf to partially hearing,
- mental handicaps including mentally retarded and brain-damaged children, for instance after birth injury,
- maladjustment due to emotional or social problems, not to mental retardation, often related to family, especially common in abused and neglected children.

Many children have multiple handicaps, the worst being those associating motor, sensorial and mental disorders. Their number is on the increase, particularly in the developed countries, due for instance to the better outlook for survival of a baby with severe congenital malformations and other disabilities, and also in developed countries where severely premature infants may survive following intensive care treatment, with lasting sequelae.

As the impairments and disabilities tend to be gradually increasing if nothing is done in terms of rehabilitation measures because of lack of facilities or too severe disorders, early detection of an even potentially handicapped child becomes a target of paramount importance.

EARLY DETECTION

- Before or during pregnancy

The extent of early screening for various impairments and potential handicaps to be routinely applied depends directly on the development of primary health care, such as the availability of repeated controls during pregnancy and after delivery. An example of very early screening is the determination of

the parents' blood group. In the case where mother is so called Rhesus factor (Rh) negative and the father Rh positive, there are chances that the baby to be born will develop a serious disability such as mental retardation. This could, however, be prevented if the Rhesus factor of the mother has been determined and the fetus of such parents is closely followed up during the pregnancy. During the first hours of delivery, the baby's blood bilirubin value has to be determined and if indicated, the blood of the baby changed (exchange transfusion). This procedure is a rather complex one and requires advanced techniques not available in many developing countries although in mild cases, less costly and complicated procedures such as phototherapy have proved quite effective. Besides, the risk to the baby may be lessened by inducing earlier delivery.

Some genetic abnormalities in the family might also warrant screening examinations of the unborn baby during the pregnancy. It has become possible by using modern techniques of analysing amniotic fluid (amniocentesis) to detect fetuses which will develop severely handicapping disabilities often of genetic origin (metabolic disorders, chromosome aberrations such as Down's syndrome), or present severe malformations, for instance of the nervous system.

- At birth and later on

Early detection of a handicap can be accomplished through different approaches, one of which is the use of various screening techniques. As an example of an important screening method, performed by the paediatricians after the birth of the infant, the test to detect a congenital luxation of the hip could be mentioned. If this condition is not detected and properly treated, the child will develop difficulties in moving around which severely influence his or her general development. Screening of some hereditary dis-

eases is also being performed early after the birth. This is the case for diseases such as phenyl-ketonuria (PKU) which, if not treated very early by an appropriate diet, will result in lasting brain lesions and definitive mental retardation; hypothyroidism, with similar sequelae is also increasingly screened.

One of the most important screening "instruments" for early detection of potential handicaps is the child's parents. They should be taught the basic characteristics of normal motor and mental development so that they may contact the appropriate health workers (pediatricians, social workers) either privately or in institutions such as MCC Centres, should some retarcation with respect to the infant's growth occur. For instance, severe hearing defects could in many cases be identified or suspected within the first 7 to 8 months of life. This is considered to be the optimum period to start special measures in order to ensure the best possible integration of the child to the society of the hearing.

In countries with a well developed network of children's health centres, no special screening measures, in addition to regular check-ups by a nurse or by a physician, are required. The measurement of height, weight, and follow-up of intellectual development constitutes per se an important screening instrument and assists in early detection of any deviation from normal development, warranting a more detailed examination of the child. Screening for visual acuity, hearing defects and postural defects helps in early identification of the school-aged children in need of some corrective measures. There are now many well standardized growth curves (for instance, those of WHO and of the International Children's Centre Growth Studies) and psychological, hearing and visual tests, which can be used both in developed and developing countries.

While the early screening methods, including education of parents, have already brought about good results with regard to early detection of impairment in many developed countries, the situation in developing countries and particularly in the areas characterized with poverty, malnutrition, illiteracy and superstition is still highly unsatisfactory. Although in these countri s particular emphasis would have to be laid on the prevention of many disabling illnesses special methods for early screening will have to be developed. The screening activities must be well incorporated in and co-ordinated with the basic health services, in order to guarantee that the handicapped child will be taken care of.

PREVENTION OF HANDICAPS

Preventive measures are also of major importance, permitting either to alleviate the severity of a handicap, or to prevent it completely. In all countries of the world, one of the major causes of motor handicap, poliomyelitis, has been totally or nearly totally eradicated by mass immunization campaigns. For instance, before mass immunization, there were on average 40,000 yearly cases in the USA, less than 10 after; in Japan, some 2,500 and 0 !; in the UK, some 4,000 and under 10. In tropical countries, in India or Guatemala for instance, partial or even total blindness has been often prevented by the early administration to infants of vitamin A, as vitamin A deficiency results in severe corneal lesions. In developed countries, like France, Sweden, the US, it has been possible through screenings and health check-ups of infants and young children to detect early minor physical, sensorial or psychological anomalies which, if they had not been treated early, would have conducted to lasting severe handicaps.

INTEGRATION OF THE HANDICAPPED

It is common experience that impairments and disabilities have many consequences to the child and to his or her family as well as to the society. Some of these consequences are directly connected with the functional limitation preventing the child from enjoying normal peer contacts and other social and educational activities, typical for his or her age. In some countries the handicapped child is not accepted to go to normal school, sometimes due to the negative attitude of the teachers and/or the families of normal school children. There are also problems arising from the attitudes of the parents, which sometimes may lead to an overprotection of the child and cause emotional problems such as overdependence and immaturity. In some cultures, the parents' attitude may be mainly negative and the child is hidden or even maltreated.

a) Family Integration

The birth of a congenitally disabled child in the family may cause reactions different from those caused by a handicap acquired later in life. These reactions depend, however, on many factors, such as the emotional maturity and education of the parents as well as intrafamily relationship. In any case, the handicapped child needs much more of the parents' time and consideration and is sometimes experienced as a burden, including an economic one to the family. The siblings may also become jealous or develop negative attitudes towards the handicapped brother or sister. All this may cause permanent disturbances in the whole family relationship. These consequences tend to become worse with time passing unless appropriate measures are taken to diminish them. In some instances, the help of a social worker or a psychologist may be necessary to overcome such difficulties.

b) Society / Community Integration

As to the consequences to the society/community, much depends on the attitude to the handicapped in that particular society. Rehabilitation is still today considered in many countries as a luxury, necessitating big investments on special institutions and specialized manpower. This will often be reflected in complete negligence with regard to what can be considered basic services for the families with handicapped children. However, there are examples that, even in very poor countries, the situation is changing.

The term "social integration" could be defined as an objective and end-point in the rehabilitation process which consists of medical, educational, psychological, social and vocational aspects. It means that the capacities of the child, within the limitations caused by his or her handicap, are being fully utilized for his or her wellbeing. All of the obstacles referred to before will severely hamper the social integration of the handicapped child.

What measures should and could be taken in order to facilitate the social integration of the handicapped ? The problem is fairly different in the developed and in the developing countries.

In the developed countries there has been an overemphasis on the institutionalized care of the handicapped children. While institutions will also in the future be required for the most severely disabled, they may constitute a real danger for successful social integration in isolating the child from his or her natural environment, the home.

c) School Integration

Increased attention should also be paid to integration of the child into the normal school ("main-streaming") and other educational and vocational services whenever possible. As the schools as well as other public buildings are often constructed for the able-bodied only, the barrier-free design should receive much more attention. No individual rehabilitation measures can overcome the architectural barriers such as a sports hall into which there is no access for a handicapped using a wheelchair. Attention should be paid to this problem whenever possible and, more generally, to any lack of facilities or equipment, which may impair or prevent the handicapped child's integration. In some instances, school integration will be possible only if transportation to get to work is available.

d) Rehabilitation in developing countries

In the less developed countries the main emphasis should apparently be in building up a rehabilitation services network as a part of the primary health care. When basic medical services are available, the integration of the handicapped children could start by appropriate case finding, perhaps using household screening, community by community. The medical problems, such as provision of technical aids, could in many cases be economically solved by using local materials for the preparation of at least some of them. When the most urgent medical problems have been taken care of, the parents should be encouraged and trained to supervise their child's locomotor and other development and further the peer contacts and play activities. Whenever possible, the child should go to a local school, to be finally integrated prefer-

ably in the local community, or elsewhere, depending on the severity of the handicap.

The community training of the disabled as described above, would not require costly investments, and would be applicable in many types of communities in less developed countries. This approach is currently one of the major elements in the WHO Programme on Disability Prevention and Rehabilitation and is being tested in several countries. Similar projects are also included in the Programmes of UNICEF, UNESCO and other UN-Organizations, as well as in many countries where the governments, private institutions, local communities are increasingly concerned with the problems of the handicapped on which world interest will be especially focused in 1981, the "International Year of Disabled Persons".

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SCREENING AND SOCIAL INTEGRATION OF HANDICAPPED CHILDREN

A DOCUMENT FOR NURSES, MIDWIVES, SOCIAL WORKERS, TEACHERS AND PARENTS

Introduction

Handicap means "the disadvantage or restriction of activity caused by disability." In a broader sense, a handicapped person can be described as one who suffers from any continuing congenital or acquired disability of body, intellect or personality which is likely to interfere with his/her normal growth, development and capacity to learn.

The size of the problem of the handicapped varies from country to country. In most countries, at least 10 percent, and possibly even more than 15 percent, of the population require special care or help because they are disabled. Some of the handicapped have been crippled from birth and have never had the chance to function as normal individuals. Others are the victims of diseases or accidents that cause them to remain physically handicapped for life. Especially in developing countries, where maternal and child care services are not adequate, natal and postnatal factors increase the total number of victims.

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The causes of handicaps are different in developing and developed countries. For example : deafness due to otitis media, blindness due to neonatal infections or trachoma, muscle weakness due to poliomyelitis, cardiac pathology due to streptococcal infections, or sequellae due to tuberculosis or osteomyelitis are still the main handicapping conditions in developing countries. In developed countries, handicaps may be genetic in origin or due to infective and/or chemical damage to the development of the fetus, or to perinatal or neonatal illness or to trauma and/or infection in childhood. In many cases all of the above involve the central nervous system and this fact leads to multiple handicaps involving hearing, speech, sensory, cognitive functions, and intelligence.

With improved methods for assuring the life of each newborn infant, the likelihood of that infant being born with potentially handicapping conditions increases. Other children are born with no handicaps, but as the result of disease or accident, may in fact acquire handicapping conditions.

The costs to society, to the family and to the handicapped child are so great in terms of suffering and expenditures that most nations have programs addressing the problems of the handicapped. A major focus receiving increased attention is early identification of handicaps in order to prevent their continued progress and to intervene with corrective actions. Another major focus is the role of the family in helping the handicapped child develop fully. And still another focus is the socialization of handicapped children, particularly through mainstreaming. These foci shape the structure of the information presented here for service providers and parents.

Early identification

There is no question that the sooner a handicap is identified the sooner remedial action can take place and adverse effects be reduced or eliminated. Early identification, then, is critical and is achieved through screening techniques which lead to confirmation by diagnosis. Defining screening and diagnosis is necessary to understand the differences and relationships.

Screening is a process that identifies children who need spe-

cific treatment (for example, eye-glasses or immunization shots) or who need to be referred for a diagnostic evaluation. Screening is therefore an important tool in the early identification of handicapped children.

> Screening procedures such as check lists and tests are inexpensive, quick, and easily administered. They give the screener an overview of a child's performance.

Screening essentially is the identification of a difference or deviation in some developmental aspect or performance of a child. The diagnosis is identifying the specific nature of the difference or deviation, its causes scope and complexity.

Both screening and diagnosis are concerned with identifying handicapped children. The handicapping conditions are defined in different ways in different countries, but the most generally accepted definitions are these :

Blindness - A child is blind when any one of the following exists :

> a) child is sightless or has such limited vision that he/she must rely on hearing and touch as his/her chief means of learning;
>
> b) a determination of legal blindness in the location of residence has been made;
>
> c) central acuity does not exceed 20/200 in the better eye, with correcting lenses, or whose visual acuity is greater than 20/200, but is accompanied by a limitation in the field of vision such that the widest diameter of the visual field subtends an angle of no greater than 20 degrees.

Visual Impairment - A child is visually impaired if central acuity, with corrective lenses, does not exceed 20/70 in either eye, but who is not blind; or whose visual acuity is greater than 20/70, but is accompanied by a limitation in the field of vision such that the widest diameter of visual field subtends an angle

of no greater than 140 degrees or who suffers any other loss of visual function that will not restrict learning processes, e.g., faulty muscular action. Not to be included in this category are persons whose vision with eye-glasses is normal or nearly so.

Deafness - A child is deaf when any one of the following exists :

a) his/her hearing is extremely defective so as to be essentially nonfunctional for the ordinary purposes of life;

b) hearing loss is greater than 92 decibels (ANSI, 1969) in the better ear;

c) legal determination of deafness in the location of residence.

Hearing Impairment - A child is hearing impaired when any one of the following exists :

a) the child has slightly to severely defective hearing, as determined by his/her ability to use residual hearing in daily life, sometimes with the use of a hearing aid;

b) hearing loss from 26-92 decibels (ANSI, 1969) in the better ear.

Physical Handicap (Orthopedic Handicap) - A child is crippled or with an orthopedic handicap who has a condition which prohibits or impedes normal development of gross or fine motor abilities. Such functioning is impaired as a result of conditions associated with congenital anomalies, accidents, or diseases; these conditions include, for example, spina bifida, oro/facial malformations, loss of or deformed limbs, burns which cause contractures, and cerebral palsy.

Speech Impairment (Communication Disorder) - A child is speech impaired with such identifiable disorders as receptive and/or expressive language impairment, stuttering, chronic voice disorders, and serious articulation problems affecting social, emotional, and/or educational achievement. When speech and language

disorders accompany conditions of hearing loss, cleft palate, cerebral palsy, mental retardation, emotional disturbance, multiple handicapping conditions, and other sensory and health impairments, the child should be reported under the most disabling problem. This category excludes conditions of a transitional nature consequent to the early developmental processes of the child.

Health Impairment - These impairments refer to illness of a chronic nature or with prolonged convalescence including, but not limited to, epilepsy, severe asthma, severe cardia conditions, severe allergies, blood disorders (e.g., sickle cell disease, hemophilia, leukemia), diabetes, or neurological disorders.

Mental Retardation - A child is considered mentally retarded who, during the early developmental period, exhibits significant sub-average intellectual functioning accompanied by impairment in adaptative behavior. In any determination of intellectual functioning using standardized tests that lack adequate norms for all racial/ethnic groups at the preschool age, adequate consideration should be given to cultural influences as well as age and developmental level (i.e., finding of a low I.Q. is never by itself sufficient to make the diagnosis of mental retardation).

Serious Emotional Disturbance - A child is considered seriously emotionally disturbed who is identified by professionally qualified personnel (psychologist or psychiatrist) as requiring special services. This definition would include, but not be limited to, the following conditions : dangerously aggressive towards others, self-destructive, severely withdrawn and non-communicative, hyperactive to the extent that it affects adaptive behavior, severely anxious, depressed or phobic, psychotic or autistic.

Specific Learning Disabilities - Children who have a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which disorder may manifest itself in imperfect ability to listen, think, speak, read, write, spell, or do mathematical calculations. Such disorders include such conditions as perceptual handicaps, brain injury, minimal brain dysfunction, dyslexia, and

developmental aphasia. Such a term does not include children who have learning problems which are primarily the result of visual, hearing, or motor handicaps, of mental retardation, of emotional disturbance, or of environmental disadvantage. For preschool children, precursor functions to understanding and using language spoken or written, and computation or reasoning abilities are included. (Professionals considered qualified to make this diagnosis are physicians and psychologists with evidence of special training in the diagnosis of learning disabilities and at least Master's degree level special educators with evidence of special training in the diagnosis of learning disabilities).

Multiple handicaps : Children have multiple handicaps when in addition to their primary or most disabling handicap one or more other handicapping conditions is present.

Family involvement

Parents are usually the first to notice a deviation in their child. They draw on experience with other children or from observing the behavior of their child in a group of children of the same age. Parents can learn to screen for handicaps and should be provided with the necessary information by practitioners and other professionals. For example, a screening instrument developed by the Committee on Children with Handicaps of the American Academy of Pediatrics, New York Chapter, is easy to administer.

Rapid Developmental Screening Check List

This check list is a compilation of developmental landmarks matched against the age of the child. These are in easily-scored question form and may be checked YES or NO by direct observation.

"NO" responses at the appropriate age may constitute a signal indicating a possible developmental lag. If there is a substantial deviation from these values, then the child should be evaluated more carefully, taking into consideration the wide variability of developmental landmarks. (Adjust for prematurity, prior to two years, by subtracting the time of prematurity from the age of the child; e.g.,

a two-month-old infant who was one month premature should be evaluated as a month-old infant).

NAME : _____ Date of Birth : _____ Date of Screening : _____

AGE		DATE	
1 month	-Can he/she raise his/her head from the surface while in the prone position?	YES	NO
	Does he/she regard your face while you are in his/her direct line of vision?	YES	NO
2 months	-Does he/she smile and coo?	YES	NO
3 months	-Does he/she follow a moving object?	YES	NO
	Does he/she hold his/her head erect?	YES	NO
4 months	-Will he/she hold a rattle?	YES	NO
	Does he/she laugh aloud?	YES	NO
5 months	-Can he/she reach for and hold objects?	YES	NO
6 months	-Can he/she turn over?	YES	NO
	Does he/she turn toward sounds?	YES	NO
	Will he/she sit with a little support (with one hand)?	YES	NO
7 months	-Can he/she transfer an object from one hand to another?	YES	NO
	Can he/she sit momentarily without support?	YES	NO
8 months	-Can he/she sit steadily for about five minutes?	YES	NO
9 months	-Can he/she say "ma-ma" or "da-da"?	YES	NO
10 months	-Can he/she pull himself up at the side of his/her crib or playpen?	YES	NO
11 months	-Can he/she cruise around his/her playpen or crib, or walk holding on to furniture?	YES	NO
12 months	-Can he/she wave bye-bye?	YES	NO
	Can he/she walk with one hand held?	YES	NO
	Does he/she have a two-word vocabulary?	YES	NO
15 months	-Can he/she walk by him/herself?	YES	NO
	Can he/she indicate his/her wants by pointing and grunting?	YES	NO
18 months	-Can he/she build a tower of 3 blocks?	YES	NO
	Does he/she say six words?	YES	NO

24 months	-Can he/she run?	YES	NO
	Can he/she walk up and down stairs holding rail?	YES	NO
	Can he/she express him/herself (occasionally) in a two word sentence?	YES	NO
2,5 years	-Can he/she jump lifting both feet off the ground?	YES	NO
	Can he/she build a tower of six blocks?	YES	NO
	Can he/she point to parts of his/her body on command?	YES	NO
3 years	-Can he/she follow two commands involving "on", "under", "behind"? (without gestures)?	YES	NO
	Can he/she build a tower of nine blocks?	YES	NO
	Does he/she know his/her first name?	YES	NO
	Can he/she copy a circle?	YES	NO
4 years	-Can he/she stand on one foot?	YES	NO
	Can he/she copy a cross?	YES	NO
	Does he/she use the past tense, properly?	YES	NO
5 years	-Can he/she follow three commands?	YES	NO
	Can he/she copy a square?	YES	NO
	Can he/she skip?	YES	NO

Parents and other family members can be taught how to use this screening instrument. In addition to being involved in the screening of their children, parents can be involved in the corrective plan developed after professionals have made a thorough diagnosis. Parents can carry out activities to stimulate the development of their children; they can remember or record changes and progress in their children; they can be given the necessary diet or guidance for their children; and they can be told what behaviors of their children indicate a need to alert the professionals. In some countries, this kind of parent involvement in corrective programs for their handicapped children is required by law.

In other countries, as in France and Sweden, early screening of handicaps is also carried out in specialized Health Centers. In Sweden, all parents may bring their children at the age of 4 years to Children's Health Centers where they will have a complete physical examination with the objective ofdiscovering minor, orthopedic or neurologic handicaps, impaired hearing or sight. The

There is growing interest in parents becoming partners with professional staff in helping handicapped children. Professionals draw heavily on information provided by parents to make diagnoses and need parents to help carry out corrective programs. Professionals are increasingly sharing their skills and authority with parents.

Parents need to be given specific information on what activities to engage in with their handicapped children to provide development. Professionals can furnish that information verbally, through demonstration or through published booklets.

psychologic examination seeks to detect the early onset of developmental and social adjustment aberrations. At the age of 7, upon school entrance, all children are again examined specially to detect orthopedic, behavior and visual disturbance.

In France, Health check-up are carried out in a few Pilot Centers in children at 10 months, 2 years and 4 years. The chek-up includes a physical examination and a careful investigation of vision and hearing. The psychologic examination aims at the detection of psychomotor developmental and interpersonal relationship problems prior to school entrance. In Sweden and France, these examinations, performed at no cost to the families, result in the detection of many handicaps. However, their cost makes it nearly impossible to duplicate them in "developing countries". Simplified modifications of these programs must be prepared for the non-industrialized countries, where their introduction and use should be considered essential.

Besides specialized Centres, in some countries like the German Federal Republic or France, health examinations made legally compulsory permit to develop early mass screening of handicaps.

Socialization and mainstreaming

Each person living in a society has to learn basic social skills to satisfy his/her personal and social needs. The handicapped also need these skills, but have difficulties in acquiring them not only because of his/her disabilities, but also because of the neglect of the society. Therefore, a handicapped child may be socially isolated or segregated unless special care is taken. The following points indicate why this special care should be taken for the social integration of the handicapped :

- Like everybody else, the handicapped child is a human being with the right to be a functional member of the society.
- Without social integration, the handicapped is a burden to the society. The absence of social skills results in an unsuccessful vocational life, and consequently, the handicapped will be a consumer only without producing. Social integration motivates the handicapped to work.
- Social integration of the handicapped will protect their parents from a heavy emotional burden.

- Most parents feel responsibility for their handicapped child. They will look after this child for all his/her life if he/she is not socially integrated. Social integration will save the parents from a heavy financial and moral burden.

Everybody who feels responsibility for the well-being of the handicapped should take part in the socialization process to train him/her as a productive member of the society. The most active agents of this process are the parents of the handicapped. The parents trained in the social integration of their handicapped child will apply not only the socialization principles at home, but also will engage in regulating the child's interaction with the environment outside the family.

The following conditions seem to be necessary for the social integration of the handicapped :

- The parents should accept their handicapped child with his/her handicaps and not compare the child with siblings and peers. Their behavioral expectations from this child should be realistic.
- The handicapped child should perform his/her own daily routines such as dressing, walking, eating, etc. He/She should be encouraged to solve his/her own problems with the help of others where necessary.
- The handicapped child should participate in the work performed at home. He/She should not be assigned work that he/she is not able to carry out, but he/she should feel responsibility for the essential works he/she is able to do.
- For the handicapped, vocational training suitable to his/her handicaps is essential. Skills to produce something facilitate the development of a realistic self concept which plays an important role in the process of the sucessful social integration of the handicapped.
- Most parents of a handicapped child tend to feel guilty about the disabilities. They think that they are responsible for their child's abnormality. These feelings may lead them to overprotect their child. The overprotection delays the child's social integration, because the social environment does not protect the handicapped as his/her parents do, and

consequently the child avoids involvement in social activities. Furthermore, overprotection does not allow the child to learn to deal with his/her own problems. With proper counseling, the parents may discontinue such feelings that hinder the social integration of the handicapped.

- The parents should not hide their handicapped child from others outside the family. They should take him/her everywhere the child can go, such as playgrounds, shopping, and visits, in order to provide the child with an opportunity to know others and to learn how to interact with them.
- Everybody who is involved in the training process of the handicapped should have patience because the time needed for his/her progress is much longer than the time for the non-handicapped peers.

Mainstreaming is a special kind of socialization. It is based on the value that children must be regarded as human beings to be part of the larger society and not as handicapped children to be isolated or segregated. Mainstreaming in schools is a relatively recent concept and involves mixing handicapped children with non-handicapped peers. There are at least six mainstreaming options a school may adopt, depending on available facilities and the severity or complexity of the handicapping conditions. These six options are as follows :

1. complete mainstreaming of handicapped child into a regular classroom (no supportive assistance)
2. complete mainstreaming of handicapped child into a regular classroom with support assistance provided by a specialist
3. complete mainstreaming of handicapped children in a classroom where the regular classroom teacher and a special education teacher cooperatively work with all children (a team arrangement)
4. reverse mainstreaming in which normal children become part of a special education class
5. partial mainstreaming where handicapped children are in a special education class but go to mainstreamed classes for one or more regular classroom activities
6. handicapped children receive service from the program but are not mainstreamed

The Head Start Program in the United States of America, a program for children from families with low incomes, has a requirement to include in their enrollment 10 percent handicapped children. These children are to be mainstreamed according to the six options identified. A careful study was conducted to compare the process and supports for mainstreamed Head Start and non-Head Start children and to compare the relative costs. The socialization benefits of mainstreaming in Head Start were also noted. The findings are these :

* More than 90 percent of the Head Start children included in this study were completely mainstreamed in the sense that they spent nearly all their program time in the company of non-handicapped peers. Fifty-four percent were in mainstreaming situations in which services were provided by professional specialists to augment core Head Start staff capabilities.
* Only 13 of the 46 non-Head Start programs visited provided a classroom mainstreaming experience. However, in each of these 13 programs, the regular classroom teacher was provided supportive services by professionals and specialists.
* The nature of a child's handicap and the severity of the handicap affects the mode of mainstreaming only slightly. Severely disabled children were more likely to be in mainstreaming settings in which the Head Start classroom teacher received supportive services.
* Most children who were considered to be "completely" mainstreamed spent over 90 percent of their time in a typical day in the company of non-handicapped peers.
* More than 66 percent of the 269 children observed were judged to be fully integrated into classroom activities. Children diagnosed as mentally retarded or emotionally disturbed were less likely to be fully socially integrated than children with other handicaps. Fifty-seven percent of those children with severe or profound disabilities were judged to be socially integrated whereas this was so for 81 percent of those children with mild impairments.
* In nearly 85 percent of all informal in-class observations conducted by field staff, the focus child was observed in a group structure that included non-handicapped peers. In only 5 percent of these observations was the focus child involved in social situations that included only handicapped children.

Types of Handicapping Conditions of Children Being Served by Full Year Head Start Programs

Handicapping Condition	Number	Percent of Total Number of Children Professionally Diagnosed as Handicapped
Speech Impairment	21.988	53.2
Health Impairment	5.118	12.4
Serious Emotional Disturbance	3.007	7.3
Physical Handicap	2.915	7.0
Mental Retardation	2.742	6.6
Specific Learning Disability	2.297	5.6
Hearing Impairment	1.637	4.0
Visual Impairment	1.340	3.2
Deafness	0.162	0.4
Blindness	0.133	0.3
TOTAL	41.339	100.0

* Facilities and materials available to Head Start programs to support the mainstreaming handicapped children are generally adequate for children with mild or moderate impairments. Head Start programs, though, often do not have the special equipment or materials that would facilitate the delivery of services to severely handicapped children.
* Pupil expenditure ratios, both in terms of total funding available and funding earmarked specifically for the handicapped, are substantially higher in non-Head Start programs.

As with all Head Start centers, parents are required to be involved with their children and the program. For parents of handicapped children, their involvement included information, training and participation in the following areas :

- program goals and objectives
- normal child growth and development
- identifying special needs of their children
- educational planning
- availability of other community resources
- legal rights related to their child
- genetic counseling
- information concerning their child's specific handicap
- home management of child/activities for parents to do with child

Parents in other programs where children are mainstreamed and parents must be involved, participated in similar fashion.

Summary

There are adequate screening instruments and diagnostic techniques available to make early identification of potentially handicapping conditions possible. Early identification of potentially handicapping conditions permits early intervention and correction of potential problems. The family is critical in both helping identify deviations in their children's development and in helping with the corrective program. The socialization of handicapped children is vital to the children, their parents and to society. Many people need to be involved in the socialization of handicapped children. One successful technique is mainstreaming.

This is the distribution of handicapping conditions among children mainstreamed in Head Start in the United States of America. The high incidence of speech impairment may be for two reasons :

a) there is a long history of interest in speech impairment; and
b) speech is seen as very critical to learning. Other countries will very likely have different distributions.

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SCREENING AND SOCIAL INTEGRATION OF HANDICAPPED CHILDREN

A DOCUMENT FOR ACADEMIC LEVEL WORKERS AND PROFESSIONALS

The role of screening in medical practice

Whilst screening has now become a major preventive function within all national health services, it is important to remember the theoretical basis on which its use must be founded. Medical screening of total populations is undertaken mainly for two reasons. First, epidemiological measurements can be made to assess incidence rates of specific disorders and their geographical, social and temporal variations within the population. This information is of great value for forward planning for the provision of health, educational and social services for many disorders including all kinds of handicaps. Secondly, screening is used clinically to identify preventable disorders. This latter function is used in two ways, first for the primary prevention of a disease and secondly to control or minimise the potential ill effects of an established disorder at an early stage, before the symptoms have become obvious and the condition unresponsive to treatment.

Cochrane and Holland (1971) have pointed out that before a screening procedure can be justifiably introduced on a national basis for clinical purposes, it is necessary to show that:

(1) The disorder which the screening procedure identifies is one for which treatment of proven value exists and is readily available.

(2) The screening test is itself reliable, without an excess of false negative or positive results.

(3) The screening test is simple to apply on a universal basis and acceptable to those to whom it is administered.

(4) The cost of the screening test is one which is financially acceptable. This means that some tests which may possibly provide

International Year of Disabled Persons 1981

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some benefit at considerable cost for relatively few people have not been considered to have justified their inclusion in a national screening programme.

In all aspects of screening in medical practice, there is also an important difference from all other conventional medical care. If a patient asks for medical help, the practitioner does the best he can, whatever the nature of the illness. If, however, the medical practitioner initiates the procedure, he is in a very different situation. He should have conclusive evidence that the screening procedure he is offering is one which will identify a disease for which he has effective treatment for at least a significant proportion of those affected by it. This approach to screening is rather restrictive but, according to local socio-economical conditions, it may be less strictly applied.

Early screening of handicaps

Primary prevention (Before conception)

Primary prevention of handicaps is now possible if particular factors are identified by screening in a limited number of conditions. In rhesus incompatibility for example, a mother who is found during her first pregnancy by routine screening to have a rhesus negative blood group, if given anti-D rhesus + immunoglobulin immediately after her child is born, will not subsequently develop the rhesus antibodies which might in further pregnancies cause damage to the fetus or newborn child. Another example shows that about 15 per cent of women of childbearing age have not developed natural immunity against rubella infection. If such women contract rubella in the early months of pregnancy, the rubella

virus will cross the placenta and cause considerable damage to the fetus. Although many countries now recommend routine immunisation of infants or school girls against rubella, the immunisation coverage is in practice not comprehensive. Before a woman embarks upon pregnancy, a simple blood test will reveal whether she is immune or vulnerable to rubella infection ; should she be vulnerable, immunisation can be undertaken (provided the woman understands that she must not become pregnant during the following three months and is appropriately advised about precautions to ensure that this does not occur). In this way, any risk to the unborn child, should the mother come into contact with rubella during the pregnancy, is eliminated.

Screening during pregnancy

Screening during pregnancy for congenital malformation or metabolic diseases of the developing fetus by means of computerised tomography and amniocentesis are not justified as whole population screening procedures, but may be necessary for mothers known to be at special risk. The routine use of ultra sound as a routine screening technique in pregnancy is now under investigation.

Screening in early childhood

Birth

It can be argued that a well conducted medical examination at birth is a human right which regrettably is available to only about one fifth of the world's population of newborn infants. At such an examination, the presence of a potentially handicapping disorder may be detected. Congenital dislocation of the hip, if identified at birth, can be treated with the minimum of disturbance to the infant so that

the condition is totally corrected before the child reaches the usual age at which walking begins. If undetected, long periods in hospital, a series of surgical procedures and no guarantee of a satisfactory result are the most likely outcome. Congenital heart disease detected at birth can lead to prevention of complications and the provision of elective surgery at the optimum time for the child. Simple anthropometric measurements such as head circumference (when appropriately correlated with the infant's gestation, birth weight and length) can provide a valuable guide to any increased probability of the development of microcephaly or hydrocephalus.

The diagnosis of Down's syndrome (and of other multiple system malformations and disorders, such as other chromosomal abnormalities) at birth can be of major importance to the family. In such situations, the early diagnosis - although not fulfilling all four of Cochrane and Holland's criteria - will provide the opportunity for the family to make an earlier adjustment to the fact that their child is handicapped, and for appropriate advice and support to be made available at the earliest possible stage. There is increasing psychological and social evidence that family adjustment (using such measurements as the extent of maternal depression, and stability of the marriage relationship) is improved when the diagnosis is made early and when effective medical and social support for the family is made available right from the start.

At birth also, screening of all infants for metabolic disorders such as phenylketonuria has become standard practice in many countries. This is an example of a rare disease (occurring in only 10,000 - 20,000 births) where a cheap and effective method of detection of a disease, despite the very high proportion of negative screening tests, is justified on humanitarian terms by the prevention of mental retardation through appropriate dietary treatment. Screening for hypothyroidism is a similar example.

It is only possible in this document to describe a few examples of the potential screening value of the neonatal examination ; more comprehensive texts must be consulted for detailed information.

The first five years of life

During the first five years of life, developmental screening examinations of all children are now undertaken either routinely or in limited groups, in an increasing number of countries, for instance in France, Sweden, the U.S.A. These examinations are designed to provide developmental screening information about :

1. Gross motor function
2. Vision and fine manipulation
3. Hearing and language
4. Skills and social reactions

If the strict criteria of Cochrane and Holland are applied, only a limited number of the tests which are in common use can be technically justified on strict scientific grounds. Those which test vision and hearing are clearly justified, since very early medical treatment and developmental stimulation designed to correct or compensate for visual or auditory handicaps is of major advantage in all aspects of child learning.

The result of the detection of abnormalities of gross motor function presents a less clear pattern of benefit. Certain abnormalities such as talipes (club foot) which are amenable to orthopaedic treatment are clear examples of disorders in which early detection is of great benefit. On the other hand, cerebral palsy is a much more controversial subject. Tizard, writing in 1980, says "my considered opinion is that screening in infancy for cerebral palsy is not, in

general, conducive to human health and happiness, lest there be any misunderstanding, let me say clearly that parents who are concerned about a baby's development should receive the most expert advice available and as quickly as possible. But actively to look for cases causes more parental misery when false doubt exists than benefit when diagnosis is certain. One effect of early diagnosis is falsely to enhance the reputation of treatment".

The screening of children for skills and social reactions is a complex subject extending across the boundaries of the health, educational, social and psychological development of the child.
Bronfenbrenner (1979) has pointed out that tests of ability in young children need cautious interpretation. For example, if a child has failed to learn to read by the usual age, the reasons for such delay may possibly be related to the teaching methods and the school which the child attends and/or to certain aspects of the home circumstances of the child as much as to any specific abnormality in the particular child. Thus, a screening test may record developmental delay in achieving a particular skill, but give little or no indication of the reason for the delay. This of itself is no contraindication for carrying out a test for, in a minority of cases, it may be possible to modify the adverse circumstances which have caused the child's developmental delay ; but in many situations, the circumstances may not be amenable to modification.

The ages at which developmental screening tests are undertaken on a young child and the number of occasions on which each child is tested varies widely from country to country and indeed within parts of individual countries. There is still a need critically to assess their value. Where tests such as those which measure a child's degree of achievement of a particular skill are available, it is of importance that such a finding should :

(1) Be followed by a comprehensive multidisciplinary assessment to determine as far as possible the reason for the delay in achieving the skill.

(2) That, where remediable causes can be identified, resources should exist within the health, education and social services of the country to provide the necessary treatment of the recognized disorder.

In countries in which these two essential criteria cannot be fulfilled, the justification of routine screening becomes inappropriate and only research investigations in limited groups are of interest. It is being increasingly appreciated that a multidisciplinary approach is essential for the great majority of this work and that the purely technical medical aspects of screening undertaken in young children constitute only a minority of the assessment that is needed. There is no justification for screening of child populations for clinical reasons if the resources (medical, educational, social and economic) for the correction of the abnormality that the screening procedure identifies are not available for those individuals who are found to require treatment. However, the results of screenings may provide information on the handicap causes and thus result in therapeutic advances later on. In many countries, routine screening of the child population has taken on an increasing component of social assessment of the quality of child rearing, which has considerable relevance to the presence of childhood handicap.

The Social Integration of the Handicapped

The history of the attitudes of communities towards children born with severe deformities or mental handicap has been identified by Gliedman and

Roth (1976) as following four main reactions in chronological order :

(1) Extermination
(2) Segregation
(3) Second class citizenship
(4) The granting of equal rights as citizens.

Extermination is still practised in some primitive societies, but the early initiatives of religious orders (Christian in the West, Buddhism in the East) helped to produce a more caring attitude towards those unable to fend for themselves.

It is for each country and for each of us in the community in which we live to determine which of the four stages is achieved in our own country or area. For most countries and communities, the major step that need to be taken by and for the handicapped to achieve equality of rights as citizens are social in nature and have implications for all sections of each local community. The medical, health and educational needs of the handicapped are demanding, but even in the best services can be largely nullified if there is a failure by society to recognize their responsibility to accept the handicapped as equal members within their community.

Information of the families

Social integration of the handicapped needs to start as soon after the handicap has been identified as possible. It needs to involve the whole family of the handicapped individual. Parents of handicapped children need right from the start :

(1) As much information as possible about the nature of their child's handicap.

(2) To be taught the skills to manage their child's handicap themselves as far as this is possible without overdependence upon professional help.

(3) Family support.

Information is available to parents from two main sources, professionals and from other families with handicapped children. The two sources of information are complementary to each other. From this combination of information, the family cannot only gain insight into the nature and cause of their child's disability and indications of the probable long term outcome, but also moral and practical support from their local community.

The skills necessary to care for and treat a handicapped child can be taught and learned. Again both professional expertise and the experience of other families who have had similar experiences with which to contend are needed. Parent groups who meet to discuss particular aspects and problems connected with their handicapped children (often in the company of a professional health, social or educational expert) help the new family with a handicapped child to overcome their feelings of isolation and instead to develop a more positive approach to the care of their child. Almost all parents of handicapped children will at different times experience feelings of rejection of their child ; it is a most therapeutic experience for them to discover that they are not unique in this respect, but that other families have identical experiences.
The movement towards the integration of handicapped children into the normal kindergarten and educational system rather than their isolation in special insti-

tutions is another major move in the direction towards improved social integration of the handicapped into the normal community ("mainstreaming").

A family support unit which provides short term (day or short term residential care) for handicapped children, if organised on an informal and easily accessible basis, is an invaluable support to many families who find themselves responsible for the constant management of a highly dependent handicapped child. Such a responsibility is an exhausting and demanding one for the family - especially the mother - and the knowledge that she can at any time share this responsibility for the care of her child with the family support unit is a helpful integration of the most practical kind.

Information of the community

Finally, if society is to respond to the needs of handicapped children and their families, there has to be a change in approach by "the man in the street". The handicapped tend to be regarded as strange, it may be difficult to interact and communicate with them and ordinary people may be ignorant of their problems or how to respond to them. In the past, this has sometimes lead to a domination of the handicapped by the non-handicapped (a familiar trend by society in its attitude to any group of "second class citizens"). Now all this is changing in many countries and a new approach which it is hoped will provide a less isolated and segregated existence for the handicapped and finally full participation as citizens with equal rights is beginning to emerge. This new attitude can be given the right start if the handicap is detected very early (initially by the screening methods here described) and the social integration of the child and his family is begun right from the start.

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SCREENING AND SOCIAL INTEGRATION OF HANDICAPPED CHILDREN

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A DOCUMENT FOR MASS MEDIA SPECIALISTS

49

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FACTS ABOUT HANDICAP

In many countries, at least 10% and possibly even more than 15% of the population require special care or help because they are disabled.

The distribution is uneven throughout the world due partly because of great differences in the socio-economic state of development.

By the year 2000, the number of children under 15 who are handicapped will increase by about 35% unless effective preventive measures are introduced.

Poverty is one of the most important factors favouring various forms of disability : for instance, in some countries, the population cannot even afford the cost of polio immunization !

Enough is known already to reduce the number of handicapped considerably. It involves money and endeavours to improve care of the mother and child before, during and after birth as well as better immunization programmes, nutritional supplementation and campaigns to reduce childhood accidents. These PREVENTIVE MEASURES may dramatically reduce handicaps such as paralysis (polio immunization), blindness (vitamin A supplementation in tropical countries) or lasting orthopedic disorders (accidents prevention campaigns).

MAJOR AREAS OF ACTION

There are three main areas where efforts are needed :

1) The early identification of handicap by screening ;
2) Helping the family to help itself ;
3) Bringing about the integration of the handicapped in the community.

Early identification is achieved by screening. Using check lists of normal development, it is easy to spot when a child is different in some aspects. Parents are often the first to notice that "something is wrong". They are screening naturally by comparing their child with other children. Their observations are valuable. Once this is realised, the specific nature of the difference must be diagnosed and remedial action taken. However, at birth or just after, the child may look normal and special studies may be required to detect a handicap.

THE MASS MEDIA SHOULD GIVE PUBLICITY TO THIS TO ENCOURAGE PARENTS TO BE AWARE OF HOW IMPORTANT THEIR ROLE IS AND TO PERSUADE PROFESSIONALS WHO MAY STILL NEED CONVINCING.

PROFESSIONAL SCREENING SHOULD TAKE PLACE
AT THREE PERIODS :

a) Screening during pregnancy

Some mothers are known to be "at risk" of having babies with a genetic or metabolic disorder, e.g. Down's syndrome which is caused by chromosome abnormality and can be detected in the foetus.
A test called amniocentesis which involves taking samples of the fluid around the foetus, culturing the cells in it and testing them can reveal disorders causing handicap.
It is expensive and is therefore not available to the whole population of pregnant mothers in developed countries, but to the population known to be at risk.

However, good antenatal care of all mothers can reduce the chance of handicap due to brain damage before and during birth.

b) Screening at birth

All the newborn babies should have a thorough examination at birth. If disorders are detected early, something can often be done : e.g. congenital dislocation of the hip is relatively easily corrected if detected at birth.
If the detection is one year later, surgery is needed and, success not assured.

It is also at birth that some metabolic anomalies, often resulting in mental retardation, can be detected and effectively treated : e.g. phenylketonuria, hypothyroidism.

c) Screening during childhood

Vision, hearing, language development, movement and social skills can all be screened and if abnormalities are detected early, the bad effects on the child's life can be reduced.

FAMILIES OF HANDICAPPED CHILDREN N E E D

1) As much information as possible and as early as possible.
2) To be taught the skills to help their own children.
3) Support from the wider family, community and professionals.

THE MASS MEDIA HAVE A ROLE TO PLAY IN EMPHASIZING THIS AND GIVING PUBLICITY TO SUCCESSFUL SUPPORT SCHEMES WHICH EXIST.

The community and handicap

In the past, in developed countries, there has been an overemphasis on the institutional care of the handicapped. This still is an important part of the care of the severely and multihandicapped, but the dangers of segregation and isolation of the less severely handicapped from the family and community are now recognised. Increased attention is for instance being given to integrating handicapped children into the normal school system. This is called mainstreaming and countries like the United States have considerable experience in this.

In developing countries, a rehabilitation network needs to be set up as a part of primary health care. The child can then develop fully within the limitations of the handicap. Here too, it is important for parents to learn how to help their own children.

ATTITUDES TO HANDICAP

For the true social integration of the handicapped, changes have to occur at all levels.

Parents need support and advice to help them accept the handicapped child for what he/she is and not expect unrealistic achievements.

The handicapped child should not have everything done for him. Daily routines of washing, dressing, eating, etc... should be taught and practiced.

Vocational training suitable to his/her handicap is essential. We all feel better when we have a part to play in society.

With proper counselling, parents of handicapped children can overcome their feeling of guilt and desire to overprotect the handicapped child.

THE MASS MEDIA CAN GIVE PUBLICITY TO THESE IDEAS AND SHOW THEM WORKING IN PRACTICE.

Finally, we all need to change the image of the handicapped as "different and frightening". A less isolated existence for them requires knowledge and understanding on the part of the rest of us. This is a vital educational role for the mass media to play.

1981 IS THE INTERNATIONAL YEAR
OF THE DISABLED PERSONS.
IF YOU ARE NOT ALREADY PLAYING YOUR PART
IN PUBLICISING
THE NEEDS OF THE HANDICAPPED,
IT IS A GOOD TIME TO START.

INTERNATIONAL CHILDREN'S CENTRE, PARIS.
1980